

# ETHICAL CONCERNS IN USING PUBLIC DATA SOURCES: ISSUES IN ACCESS AND LINKAGE

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**Background and Aims:** Public health research and practice often have been facilitated through the evaluation and study of population-based data collected by local, state and federal governments. However, recent concerns about identity theft, confidentiality, and patient privacy have led to increasingly restrictive policies on data access, often preventing researchers from using these valuable data. We believe that these restrictions, and the research impeded or precluded by their implementation and enforcement, have had a significant negative impact on important public health research. Further, the details of the regulations vary greatly across the administrative jurisdictions that control access and manage the data. We present a case study.

**Methods:** We requested individual level birth certificate data from several states for use in a series of analyses investigating the possible association between environmental exposures and birth outcomes using public data. We also explored some strategies to overcome some of the access obstacles without violating the regulations.

**Results:** Some states provided exact maternal residential locations and residential histories, enabling us to conduct the planned analyses, while others would not release precise maternal residence location, limiting our ability to link birth outcomes to local neighborhood and environmental quality data. We developed data linkage approaches with some states that enabled us to obtain the desired results without complete individual level data records.

**Conclusions:** Limited access to routinely collected health related data limited our ability to conduct studies assessing the effects of environmental exposures. In some instances, but not all, we were able to achieve our goals with particularly cooperative health departments. We welcome input on the experiences of others and ideas for overcoming these barriers. This session will be a moderated open forum to discuss the ethical dilemmas around using public data sources with a focus on identifying emerging priorities from the papers presented in this session.

## References:

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